



# Thyroid Federation International

## Thyroid Patients Worldwide

### In this Issue

Message from the Editors .....	2
<b>From the board</b>	
President's message .....	3
TFI AGM and International Thyroid Congress 2015 .....	4
Upcoming events.....	5
<b>News from the Thyroid Field</b>	
Fetal programming by maternal thyroid disease?.....	6
In Memoriam of Professor Peter Laurberg, Aalborg .....	7
Congenital thyroid diseases in Finland .....	8
Cardiovascular mortality after total thyroidectomy and TSH suppression .....	10
Thyroid, pregnancy and polar bears .....	11
A perspective on PRO in Thyroid Practice .....	12
Avoid overdiagnosis & overtreatment for low risk differentiated thyroid cancer .....	13
Why are we ignoring the most likely cause for the NAPLAN test results... ..	15
The Thyroid Jigsaw .....	16
The Thyroid Hormone Replacement for Subclinical Hypo-Thyroidism Trial.....	17
<b>International Thyroid Awareness Week</b>	
The Australian Thyroid Foundation – Thyroid Awareness Month .....	18
World Thyroid Day in Denmark.....	18
International Thyroid Awareness Week 2016 — Worldwide.....	19
International Thyroid Awareness Week in India .....	20
<b>Activities &amp; Projects of the National Organizations</b>	
Brazil: ... best accessible public information on thyroid disease .....	21
France: Patient survey: Quality of life after thyroidectomy .....	22
Germany & France: Survey – Thyroid Cancer Journey and QoL.....	23
Netherlands: Working hard for advocacy and research! .....	25
Norway: The Norwegian Thyroid Federation – 25 years .....	27
Canada: New Ideas – New People – What a difference a day makes. ....	28
India: The TCP joins TFI.....	29
USA: GDATAF 2015-16 Highlights .....	30
TFI Member Organizations.....	32

## Thyroid Federation International

Established in September 1995 in Toronto, Canada

### Founder

*Diana Meltzer Abramsky, CM BA (Canada) 1915-2000*

### Mentor & First President

Lawrence C Wood, MD FACP (USA)



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#### Member Organizations

*The names of the organizations and their current addresses are given on page 32.*

## Message from the Editors

Once again, another year has passed with the TFI. Initially, when founded in 1995, our umbrella organization included six patient associations from Australia, Canada, UK and USA. At present, our members include 21 patient-driven or patient-oriented organizations from 18 countries. In the past year, we have added India and the Philippines. We just celebrated our 8th year of International Thyroid Awareness Week (thyroidweek.com).

Last October we celebrated 20 years of service at the 15th International Thyroid Congress in Orlando, United States. To think, twenty years ago, there was no international patient organization, and only a few national organizations. Physicians had never heard of us, and communication, much less collaboration, was almost unheard of! Now, organizations are active in all the above-mentioned countries, and include joint patient-physician meetings and work-groups (like the thyroid eye disease meeting in Newcastle/England, in 2014, the ITAW, the Amsterdam Declaration, the TRUST study ...). We have had the opportunity to organize patient forums at ETA conferences for many years, as well as to run a booth, to attend conferences, to present posters and to have our President speaking at opening ceremonies.

We look forward to a bright, and busy, future, working together for the benefit of thyroid patients worldwide.

BEATE BARTÈS AND NANCY PATTERSON, EDITORS



Beate Bartès



Nancy Patterson

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### ThyroWorld

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## President's Message

ASHOK BHASEEN, M. PHARM, MMS,  
PRESIDENT, THYROID FEDERATION INTERNATIONAL

**Dear Readers,**

Thyroid Federation International (TFI) has been serving for 21 years now, and each time we meet, plan, work and spend precious personal time away from our families, the question often arises, are we doing enough? As we grow our predominantly volunteer based operations, it becomes pertinent to have more dedicated hands on deck and also funds to manage and support our efforts. We had one of the best years in terms of raising awareness and providing education during International Thyroid Awareness week. However, we have a long way to go before we can reach more countries and ensure that some basic things like iodized salt are available in every part of the world. Finding the right people and forming credible organizations that are volunteer based continue to be a challenge in Asia, Africa and the Latin America region. Our wish list and priorities include the following:

- Have good pharmaceutical manufacturers that consistently deliver quality levothyroxine
- When pharmaceutical companies make changes in their formulations they must report that to us well in advance so that we can reach out to our patients and keep them informed of those changes and what to expect with a revised formulation
- Provide credible patient information in the language that they understand
- Keep on providing the most accurate and credible information to thyroid patients
- Global reach of International Thyroid Awareness Week and World Thyroid Day
- Continue to build on the credibility and partnership with ETA, AOTA, LATS, ATA and many endocrine societies

I am sure as you read the 2016 ThyroWorld, you may think, how can you make a difference and how can you improve upon your approach to better patient outcomes? I wanted to share some of my thoughts on patient related outcomes that may be of interest to medical doctors:

- Focus on patient related outcome and develop a partnership with your patients to ensure



*Ashok Bhaseen*

they get better by providing the feedback that adds value to your Thyroid Practice

- As a doctor or healthcare professional, what can you do to educate people? Can you spare 1 hour in your year's practice to do a Q& A with patients on a public forum?
- How can you make your patients more involved in their wellbeing? Talk to them and you will be surprised how ready and willing

they are to co-operate to get better

- How can you get involved in setting up a thyroid patient organization or help an organization with education and awareness initiatives?
- We would also welcome articles for ThyroWorld that can help educate thyroid patients.

For TFI this is just a beginning as more countries are finding the need for their own patient organization. Thyroid patients can greatly benefit from local foundations in countries in Asia, Africa and South America; the key remains to find the right leadership in these geographical areas. Our members' organizations are mostly made of volunteers and some of them are physicians who put in many hours to add value to the lives of thyroid patients. TFI looks forward to helping patients and physicians from these areas of the world to set up organizations to bring education and awareness of thyroid related issues for early diagnosis and treatment.

I would like to thank all of you who have worked with TFI affiliated members and encourage our readers to develop, help and support local thyroid foundations and organizations in your individual countries. Please visit our sites at [www.thyroid-fed.org](http://www.thyroid-fed.org) and [www.thyroidweek.org](http://www.thyroidweek.org) to learn more, and do not hesitate to talk to any TFI members at the booth during the congress.

A few hours of your volunteer time can bring a positive change in a patient's life. Offer to help your local thyroid foundation, or contact us for help in setting up an organization in your country. we need your time and involvement.

## TFI AGM & International Thyroid Congress 2015

### Orlando, Florida

BEATE BARTÈS, SECRETARY, THYROID FEDERATION INTERNATIONAL

Once every five years, TFI holds its Annual General Meeting together with the International Thyroid Congress – in 2015, this was in Orlando, Florida. On this occasion, our organization celebrated its 20th anniversary. TFI was created in Toronto in 1995, by 6 organizations: British Thyroid Foundation, TED (Thyroid Eye Disease), Thyroid Foundation of Canada, Thyroid Foundation of America, National Graves' Disease Foundation and Australian Thyroid Foundation. Over the years, it has become a truly international umbrella organization, with over 20 members all over the world, participating in all major events (ETA, ATA, LATS and AOTA congress), and cooperating closely with the medical profession.

It was not only the 20th anniversary of TFI - some of its member organizations also celebrated important anniversaries: 35 years for Thyroid Foundation of Canada, 25 years for Graves' Disease and Thyroid Foundation, 20 for the Australian Thyroid Foundation, 15 for the French organization Vivre sans Thyroïde ... The Dutch Schildklierstichting (now integrated in SON) was founded in 1987, and BTF has existed since 1992.

During the AGM, we heard an interesting lecture from the IFCC C-STFT about the standardization of thyroid tests, discussed current matters and strategic plans for the future, elected the board for the coming year, made proposals



Participants of TFI's 20th AGM. Top, from left to right: Nancy Hord Patterson (USA), Beverley Garside (Australia), Bente Lasserre (Denmark), Katherine Keen (Canada), Ulla Slama (Finland). Bottom: Beate Bartès (France), Marion Hamers-van der Boer (Netherlands), Ashok Bhaseen (India).



TFI booth at the International Thyroid Congress – Beate Bartès (France), Beverley Garside (Australia), Ashok Bhaseen (India), Téofilo O.L. San Luis (Philippines)

for the upcoming thyroid awareness week ... and our annual meeting, bringing together patient representatives from around the world, was also the occasion to exchange experience about the activities in the different countries, "what worked – and what didn't work". The time always passes by much too quickly!



One of the round tables at the ATA Alliance Patient Forum.

We then attended the International Thyroid Congress at the Disney World Swan & Dolphin Resort, where TFI had a booth to present its activities. We heard various interesting scientific lectures, met thyroid specialists from all around the world, and attended the public patient forum on thyroid cancer sponsored by the ATA Alliance for patient education, with passionate round-table discussions between patients, patient relatives and doctors, about thyroid cancer, treatment options, risk assessment, over-detection/overtreatment, the "watch-and-wait" attitude.

# WHEN for Thyroid Patients

Thyroid patients will be healthier, more involved in their on-going care and have a higher quality of life:

**W**hen they are listened to, and heard, by thyroid specialists who gain insight into the person who has come to them for care~

**W**hen they have access to clear, accurate sources of information~

**W**hen their physicians are well-trained, well-informed clinicians who can, and will, inform their patients about the many aspects and considerations of their disease~

**W**hen they are referred and connected to patient support groups that are run by trained, reliable leaders who have reliable medical involvement and collaboration.

NANCY HORD PATTERSON, PhD 2013  
GRAVES' DISEASE & THYROID FOUNDATION - USA

## Upcoming Events

**September 3-6, 2016**

39th Annual Meeting of the ETA  
Copenhagen, Denmark  
[www.eta2016.com](http://www.eta2016.com)



**September 21-25, 2016**

86th annual meeting of the ATA  
Denver, Colorado  
[www.thyroid.org/86th-annual-meeting-ata](http://www.thyroid.org/86th-annual-meeting-ata)



**March 16-19, 2017**

12th Asia and Oceania Thyroid Association (AOTA) Congress  
Busan, Korea  
[www.aota2017.com](http://www.aota2017.com)



**May 22 to 28, 2017**

9th International Thyroid Awareness Week  
[www.thyroidweek.com](http://www.thyroidweek.com)  
[www.thyroidweek.org](http://www.thyroidweek.org)



**June 15-18, 2017**

16th Congress of the Latin-American Thyroid Society  
Rio de Janeiro, Brazil  
[www.lats.org](http://www.lats.org)



**September 9-12, 2017**

40th Annual Meeting of the ETA  
Belgrad, Serbia  
[www.eurothyroid.com/](http://www.eurothyroid.com/)



**September 8, 2017**

23rd Annual Meeting of Thyroid Federation International  
Belgrade, Serbia

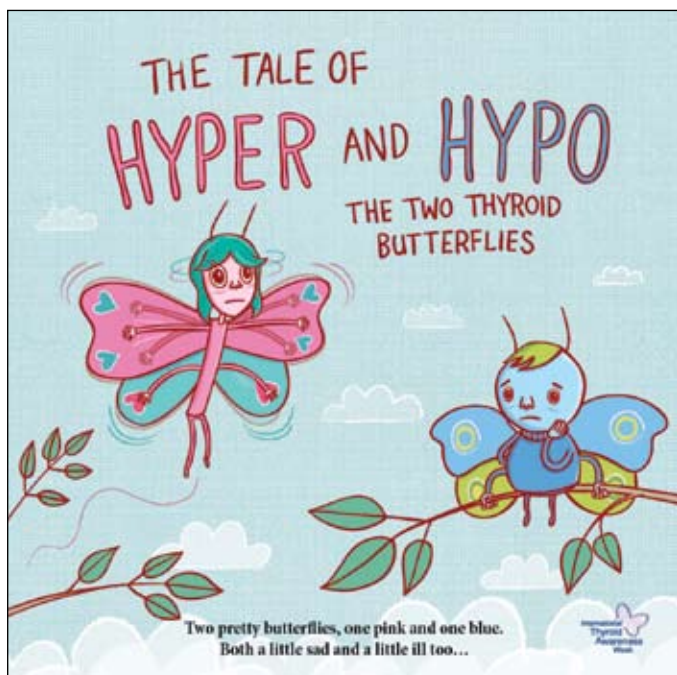


**May 25th, 2017**  
**World  
Thyroid Day**



### Thank You!

Thank you to everybody who made this issue possible, most particularly Katherine Keen, who corrected the language of all non-native speakers among our authors, and Lynda Wegner who diligently took care of the layout.



International Thyroid Awareness Week  
Storybook for Children.

# Fetal programming by maternal thyroid disease?

**Fetal programming is an emerging concept that links exposures during fetal life with the later development of disease. Considering the crucial role of maternal thyroid hormones in fetal brain development, a pertinent question is whether maternal thyroid disease may program the fetus to later development of brain related disorders.**

MD, PHD STINE LINDING ANDERSEN & PROFESSOR PETER LAURBERG, DEPARTMENT OF ENDOCRINOLOGY, AALBORG UNIVERSITY HOSPITAL, AALBORG, DENMARK

## Introduction

Thyroid hormones are important developmental factors, and maternal thyroid hormones play a crucial role in the maintenance of a normal pregnancy and in normal fetal development, especially early brain development. The fetal thyroid gland is increasingly able to synthesize thyroid hormones in the second half of pregnancy, whereas fetal development in the early pregnancy is entirely dependent on maternal thyroid hormones.

## Exposure during pregnancy

Pregnancy is a complex period of considerable physiological changes in the mother to provide for the growth and development of the fetus. Worldwide, much attention has been drawn to different so called 'exposures' during pregnancy. These are factors that may disturb the pregnancy and the development of the fetus.

Many different maternal exposures have been considered and described e.g. lifestyle habits such as smoking and alcohol consumption, environmental factors such as chemicals in food and cosmetics, and maternal diseases such as diabetes. The identification of potential risk factors is important because their control or elimination may prevent pregnancy complications.

## Fetal programming

The fetal origin hypothesis was first described in 1989 by the English scientist David Barker and his colleagues (1). They observed that men who developed heart disease or diabetes at the age of 60 or 70 years had had a lower weight at birth than those men who did not develop disease. The

interpretation was that the lower birth weight was an indicator of impaired fetal development and that permanent changes had programmed these individuals to the later development of disease.

Since then, much research has expanded the hypothesis of fetal programming, particularly within the field of nutrition and diabetes. It is, however, still uncertain if and how maternal thyroid disease may program the fetus to later development of disease (2).

## Danish nationwide registers

An opportunity to study the hypothesis of fetal programming by maternal thyroid disease emerged from the Danish nationwide health registers. In Denmark, every individual is provided a ten-digit personal identification number at birth which is used in all the nationwide registers in encrypted form and enables linkage between the registers for analyses of large datasets.

We used the Danish nationwide registers to study the association between maternal hyper- and hypothyroidism and the later development of neurobehavioral disorders in the child (3-5). Considering the importance of maternal thyroid hormones during fetal brain development, we hypothesized that any disturbance in maternal thyroid function during the pregnancy could lead to subtle changes in the fetal brain which in turn could predispose the child to the development of seizure, autism spectrum disorder, ADHD or psychiatric disease in adolescence or young adulthood.

## Maternal hyper- and hypothyroidism

We identified two groups of pregnant women with thyroid disease. One group of women had known disease at the time of the pregnancy and treatment had been initiated, but studies from several countries have indicated that women with known thyroid disease may not be adequately treated at the time they become pregnant.

The other group of women had no registration of thyroid disease before or during the pregnancy, but were first diagnosed and treated in the years following the pregnancy. Symptoms of thyroid

*(continued on page 7)*

## Fetal programming ... (continued from page 6)

disease may be unspecific, may mimic pregnancy symptoms, and may persist for a period of time before the diagnosis is made. We speculated if women diagnosed with thyroid disease after a pregnancy could have suffered from hyper- or hypothyroidism already during the pregnancy which at that point in time was undetected and untreated.

### Evidence of fetal programming?

We studied all children born in Denmark over a long period of time which provided a study population of more than one million children. Overall, we observed that children born to mothers with hyper- or hypothyroidism more often were diagnosed with seizure, autism spectrum disorder, ADHD, or psychiatric disease in adolescence or young adulthood than children whose mother did not suffer from thyroid disease (3-5).

There was one consistent and striking finding in the results of our studies. It was predominantly children whose mother was first diagnosed with thyroid disease in the years after the pregnancy who had an increased risk of developing a neurobehavioral disease later in life. This may suggest that undetected and untreated maternal thyroid dysfunction in the pregnancy could be one of the mechanisms involved in fetal programming by maternal thyroid disease.

### Perspective

The strength of studies based on nationwide registration of health data is the opportunity to study a large number of children and their mothers and to study even rare events, but it is important to be careful in the interpretation of the results. Such studies are observational in design, and our Danish studies did not include information on results of maternal thyroid function testing in the pregnancy. We can only speculate on potential mechanisms involved in the associations observed, and many other factors may also be of importance.

The hypothesis of fetal programming by maternal thyroid disease is biologically plausible knowing the crucial role of thyroid hormones during early brain development. Our findings are in line with other reports, but further studies, including studies with actual measurement of maternal thyroid function in pregnancy, are needed to expand the hypothesis.

*(continued on page 8)*

## In Memoriam of Professor Peter Laurberg, Aalborg

It can't be true, it is not OUR Peter Laurberg, there must be another doctor called Laurberg – these were my first reactions when one evening in June, I read the sad news about Peter Laurberg's death in a car accident in Tbilisi. But unfortunately it was our Peter Laurberg.



Peter has been a good friend of the Danish patient organization, Thyreoidea Landsforeningen, for a long time. He was always very helpful with patient forums and articles in our newsletter. Also Thyroid Federation International has benefited from his helpfulness during his presidency of ETA.

He was an excellent endocrinologist and world famous for his research, but I especially want to emphasize his ability of getting young doctors interested in the field of endocrinology. Aalborg University Hospital, with Peter Laurberg in front, has produced so many young endocrinologists, and he made it possible for them to do the research and present it. Most of them have stayed in the thyroid field which we as patients are very grateful for.

At the age of 71 Peter had not retired like other people and he was still very active in today's research on iodine status, and pregnancy and thyroid disease. Always interested in other researcher's results and very often present in the auditorium during the ETA conferences, listening to new research findings, very often with insightful questions or comments to the speaker.

When I am attending the scientific program at ETA 2016 in Copenhagen this September, and it is time for questions, my eyes will automatically be searching for an energetic man with a grey beard approaching the microphone, always starting his comment or question with "Laurberg, Aalborg" in his characteristic voice.

Thank you for all your work in the thyroid field for so many years. Thyroid patients will miss you, Peter Laurberg.

BENTE JULIE LASSERRE  
VICEPRESIDENT OF THYREOIDEA LANDSFORENINGEN, DENMARK

# Congenital thyroid diseases in Finland

JAANA SILTAINSUU, HARRI NIINIKOSKI AND JUKKA KERO

Congenital hypothyroidism (CH) is a condition where a newborn baby does not have a sufficient amount of thyroid hormones for the needs of the body. If left untreated, CH will lead to grave developmental disability and growth disturbances. This why CH has been screened for in Finland since the late 1970's by measuring the concentration of thyroid stimulating hormone (TSH) in umbilical cord blood. TSH screening allows immediate identification and treatment of the condition, and the consequences of the lack of thyroid hormones may be avoided. One in every 2,500 newborn has CH, which equals an annual number of 20 – 30 babies with CH in Finland. The condition may be due to poor development, malpositioning or total absence of the thyroid gland. It may also be due to poor function of the thyroid, i.e., the gland cannot produce the necessary hormones. Poor hormone production by the thyroid may also be caused by functional disturbances of the parts of the brain that control thyroid function, e.g., the pituitary.

Congenital hyperthyroidism is extremely rare and, when present, is usually due to thyroid stimulating antibodies originating in the blood circulation of the mother. Genetic factors may also cause congenital hyperthyroidism.

We have initiated collaboration with the university hospitals and the pediatric clinics in Finland to study the genetic changes behind congenital disturbances in thyroid function – hypothyroidism and hyperthyroidism. Previous

research has found that for about 20% of the patients with CH the cause is congenital. These patients have genetic alterations of the genes that are crucial for controlling thyroid function; some 15 such alterations are known. Some of these genetic changes are associated with other congenital defects and functional disturbances, e.g., in the lungs, kidneys, heart or hearing.

CH has not previously been systematically studied in Finland. Identifying a genetic aberration as a cause for the disease permits better genetic counseling and adds to our knowledge of thyroid function and the rare problems associated with CH. Genetic research methods have improved over the years, and rather than examining one genetic error it is possible with modern methods to concurrently examine several genes or even the entire genome.

For our research, we have developed a gene panel covering all known genes involved in disturbed thyroid function. This research is preliminary and awaits publishing. Thus far, 14 families with at least two members with CH are participating in the study. We have, in addition, sequenced about 30 patients with sporadic CH, i.e., patients in whose family there are no other known members with this condition. The type of CH in our study population varies: some have thyroid enlargement, some a small thyroid and some had no thyroid at all. One patient with CH has a developmental disturbance of the kidneys.

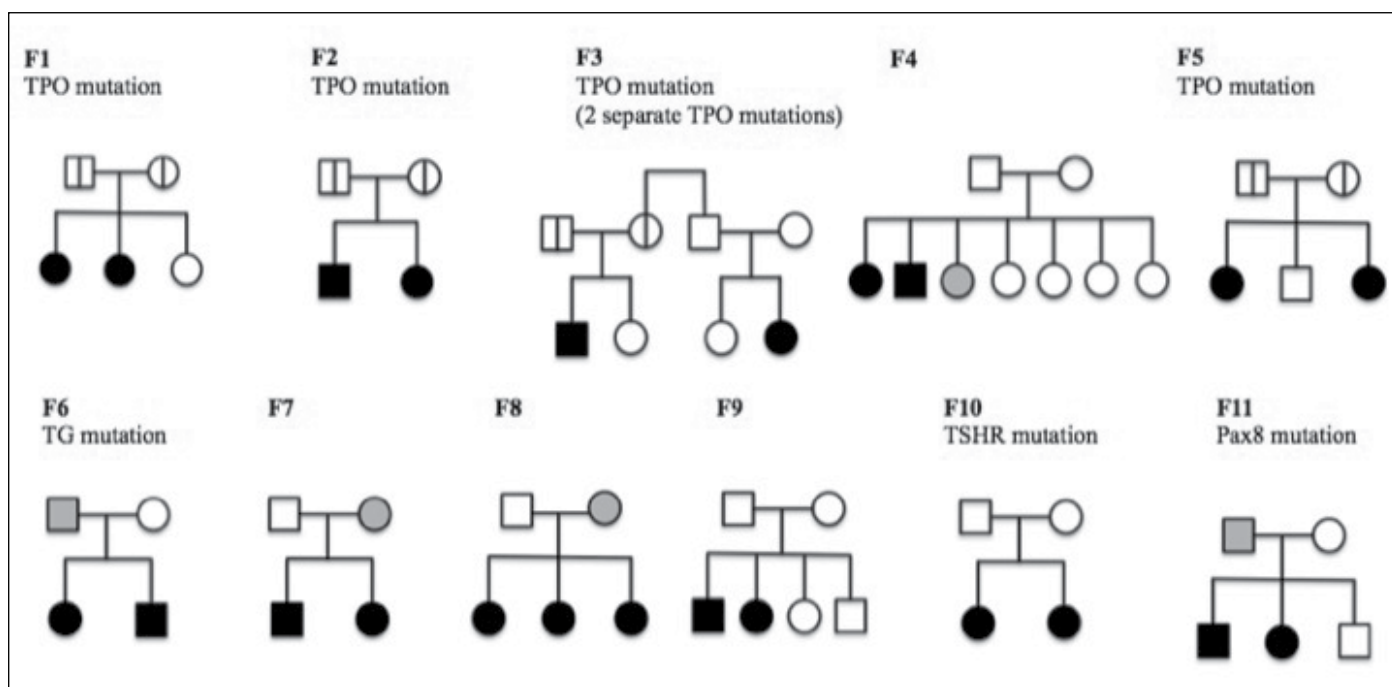
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## Fetal programming by maternal thyroid disease? *(continued from page 7)*

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Finnish families (F1–F11) with congenital hypothyroidism. The family trees have been modified and do not correspond to real families. White symbol (○ female, □ male) = no thyroid disease. Black symbol = congenital hypothyroidism. Grey symbol = hypothyroidism at adult age. Symbol with strikethrough = carrier of genetic aberration. TPO = thyroid peroxidase, TG = thyroglobulin, TSHR = thyroid stimulating hormone (TSH) receptor and PAX8 = crucial gene regulating thyroid development.

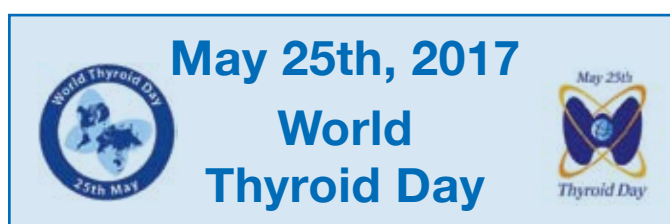
Preliminarily, we have found a genetic reason for CH in 9 out of 14 families. The figure shows examples of families with CH and the related genetic changes. The most common genetic aberration was related to the gene regulating the enzyme thyroid peroxidase (TPO), crucially involved in thyroid hormone production. This genetic change was encountered in 4 families. This is most interesting, because precisely the same genetic aberration is the most common genetic cause for disturbances in thyroid hormone production in several other populations. The Finnish genome does not seem to be any exception to this finding. We have also identified congenital thyroid disease related changes in the PAX8-gene. This gene is important for the development of the thyroglobulin receptor, TSH-receptor and the thyroid gland in general.

We have thus far analyzed only some of the data on our patients with congenital hyperthyroidism. The preliminary results show that three patients carry a mutation that causes hyperthyroidism by activating the TSH-receptor.

We are in the process of reporting the results to the families and their physicians. Work to be done also includes writing a summary of the

research and creating a broader genetic panel for sequencing among those patients with congenital thyroid disturbances for whom no significant aberrations have been found in the etiologically related genes known from before.

In our hands, the thyroid gene panel that we have created is an effective tool for identifying new as well as previously known genetic aberrations, especially in patients with CH. Our work is still in progress, but we feel that the panel we use is a valuable method for examining genetic causes of thyroid diseases in this patient group. We see, in future, recruiting additional patients, especially from families where there is more than one patient with CH or non-autoimmunological hyperthyroidism. We are most grateful to the children and their families and physicians who participated in this research project.



# Cardiovascular mortality after total thyroidectomy and TSH suppression

## Cardiovascular mortality after total thyroidectomy and TSH suppression in 6900 patients with differentiated thyroid cancer: a Swedish population-based cohort study.

### AUTHOR INFORMATION

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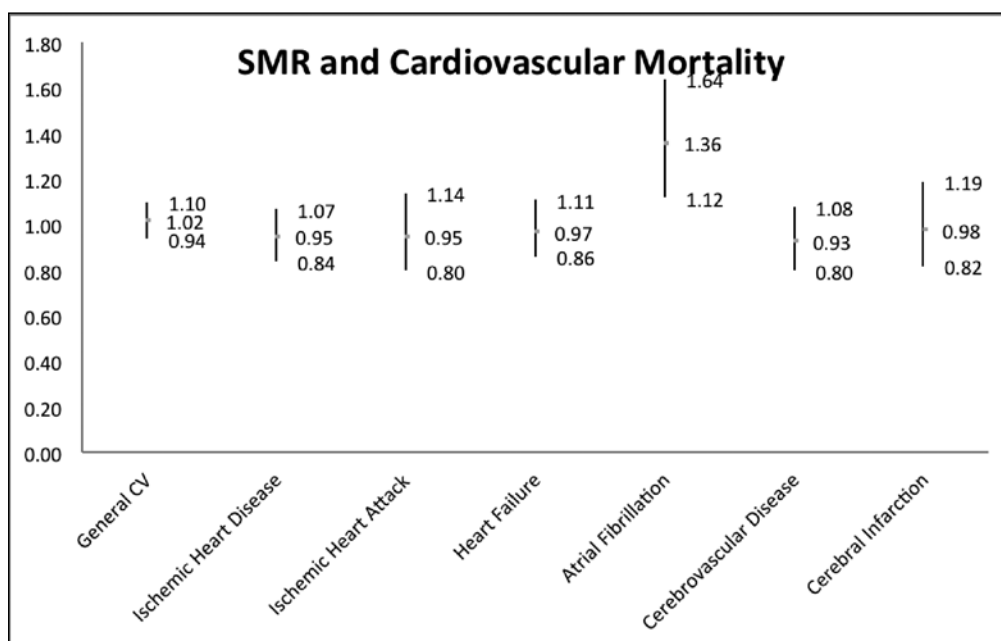
Papillary, follicular and Hurthle cell thyroid cancers all fall into the category of differentiated thyroid cancer, which accounts for more than 95% of thyroid cancers (1). The initial treatment consists of surgery and radio iodine treatment (2). After these procedures, thyrotropin levels (TSH) are suppressed with levothyroxine usually in a life-long manner, since clinical data demonstrate that TSH stimulates cancer cells (1-3). The prognosis of DTC is good, where the relative 10 year survival surpasses 90% (4). As a consequence

of the good survival prognosis, the majority of patients do not die from the thyroid cancer itself, but instead risk dying from the postoperative cancer treatment and/or other illnesses (5).

A natural consequence of TSH suppression is subclinical hyperthyroidism, which several previous studies have linked to cardiovascular (CV) diseases and mortality. To investigate if patients with DTC are at increased risk of CV mortality, we studied the whole Swedish population between 1987-2013. We compared DTC patients with the general population by using Standard Mortality Ratios (SMR), where any range overlapping SMR 1.00 indicates that the CV mortality risk of DTC patients cannot be distinguished from the one of the general population.

In general, we found DTC patients' CV mortality risk to be similar compared to the general Swedish population's, but were however able to identify some risk factors. The first finding was that DTC patients run an elevated risk of dying in atrial fibrillation (SMR 1.36) (Please see figure 1). Secondly, men with DTC were at a greater risk of CV mortality compared with women (SMR 1.16 vs 0.95). Thirdly, younger patients (<45 years) with a long duration of disease (>20 years) ran a 4-fold increased risk of

(continued on page 11)



Standard Mortality Ratios (y-axis) and cardiovascular mortality classified according to International Classification of Diseases (x-axis). Any interval overlapping 1.00 indicates a nonexistent difference between CV mortality risk in DTC patients and the general Swedish population.

## Cardiovascular mortality ... (continued from page 10)

CV mortality, which could be explained by long-term TSH suppression therapy.

The major strength of this study is the vast patient material, which includes 6900 patients over 26 years of data, collected from a high quality population register. To our knowledge, this is the largest DTC cohort study that has investigated CV mortality so far. Further, actions of precautions have been exercised in order not to over-estimate results and to strengthen the risks of CV mortality in DTC patients. These include exclusion of mortalities up to one year post DTC diagnosis and exclusion of patients with previous cancer history.

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## Thyroid, pregnancy and polar bears

ULLA SLAMA, FINLAND

The ThyroWorld newsletter of Summer 2012 reported on the polar bear Venus from the Ranua national animal park in northern Finland. Venus is the godchild of the Thyroid Patient Association of Finland. She had several miscarriages before her hypothyroidism was discovered. After that she received a daily dose of 600 mcg levothyroxine and, in November 2011, she gave birth to the polar bear cub called Ranzo. However, since then Ranzo remains her only child; Venus had more miscarriages. One reason is that it is not easy to feed a polar bear with pills. She has discovered methods to avoid the tablets and, for nurses approaching her closely, it is uncomfortable, even dangerous.

Her only cub Ranzo was sold in 2014 to a location in central Europe. We had been informed that he might be in Germany.

In April 2016, my husband and I attended an aunt's anniversary in Vienna. My husband's family lives close to the castle Schönbrunn in Vienna, where his great grandfather, Dr. Funkh, had served as physician in the court of



*Ranzo as a baby.*

the Habsburgian Emperor, Franz Joseph. While walking with my husband in the April sunshine of Vienna, we got the idea of visiting the polar bear animal park of Schönbrunn. And whom did we find there! There stood our Ranzo on two legs, playing with some small

birds. Sometimes he seemed to look far away, maybe nostalgic for the polar circle regions of northern Finland, where his mum, the godchild of the Thyroid Association of Finland, still lives with too few levothyroxine tablets and no more siblings of Ranzo.



# A perspective on *PRO* in Thyroid Practice

ASHOK BHASEEN, M.PHARM, MMS

A **patient-reported outcome** or *PRO* is a method or questionnaire used in a clinical trial or a clinical setting, where the responses are collected directly from the patient.

The focus of this article is on thyroid patients and their treatment. Information on patient's own experience of thyroid disease and treatment are valuable source of information that can be successfully leveraged by having a good patient doctor partnership for better health outcomes. This is more or less aligned with patient centricity. Patient reported outcomes (PRO) have been successfully used over the years in clinical trial settings with various measures in place. However, this article is more to do with how PRO can be beneficial in today's world where technology and information are readily available in most adult hands and more patients are well informed on their disease once they have been diagnosed by a physician or thyroid specialist.

Quality of life is a key factor for thyroid patients and they yearn to get that normal life back and want the treatment to work. As we know from talking to thousands of thyroid patients over the years, some patients are unique and what may work for majority does not work for them. Here is where patient reported outcome can help the physician in knowing and understanding what the patient is going through and come up with better treatment plan. PRO can play an important role in facilitating a prescriber in the identification of the best option for a patient that may be different from majority. A doctor-patient partnership focusing on the outcomes and coming up with a treatment plan that addresses the issues may be of great help. Sometimes a patient is allergic to some inactive ingredient in a medication that becomes a barrier in healing. Trying to know your patient better will help solve this issues, a pharmacist can provide information on the formulation of a medication that can help a doctor determine the issues. Compliance in talking the medication and not having other supplements or vitamins along with a medication are other areas that a patient may need to change and a doctor asking questions on these areas will also help in better patient outcomes. The right time of taking the medication without any other food or minerals and other precautions play an

important role in compliance e.g. for patients on levothyroxine. Managing a disease should not be a domain of a just physician or a patient, rather a partnership of the two that will lead to successful outcomes. A few minutes of dialogue will save a lot of time for both physician and patient in the long term and thyroid related disease is one of those areas which is there for a long time. With electronic records on hands now, patient related outcomes can be recorded on subsequent visits to the doctor and progress monitored. If changes in medication are needed, the electronic records can be very helpful in more positive patient outcomes.

Regulatory authorities are also placing more importance on what Patient has to say during the clinical trial rather than just focusing on clinician's report and data. It not only saves lives but also provides important information for establishing indications, safety, adverse effects, warnings and precautions, etc. We live in the information age today and doctors see this in their daily practice, today's patients are taking a more prominent role in their healthcare. It is an opportunity for doctors to adopt this in their daily practice and know their patients better.

The questions that we need to address from this articles are:

- Can we adopt Patient Related Outcomes in practice?
- Do we maintain electronic records and do we have the technology to do it?
- What proactive role if any can Patient play in helping with electronic records, that reduces a physician time in consultation?
- The merits far outweigh the disadvantages as doctors have more information to work with, is there a will to switch to something that already happens at clinical trial stage?
- How can we make PRO part of the Thyroid practice?

The intention of this article is to sow the seeds for the future so that both doctors and patients can work on leveraging patient related outcomes to improve both the quality of life and better outcomes on treatment choices made by the physicians when they have better and complete information on hand.

# Avoid overdiagnosis and overtreatment for low risk differentiated thyroid cancer

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The apparent incidence of low risk thyroid cancer is increasing and this tumor is the most frequent endocrine malignancy. It frequently occurs in young adults. The diagnosis of cancer, including of thyroid cancer may have important negative emotional, social and financial consequences for the patient. It may lead to unnecessary treatments which may induce morbidity. Also, the cost of these treatments may be important.

The recent 2015 American Thyroid Association (ATA) Guidelines have taken these points into account and recommend based on available data, a diagnostic and therapeutic strategy for the indolent forms of the disease.

## Papillary Thyroid microcarcinoma (mPTC)

The South Korean experience has clearly shown that screening with neck ultrasonography and fine needle aspiration biopsy (FNA) is the major cause of the increased incidence of thyroid cancer observed over 3 decades in all industrialized countries: in South Korea, since the beginning of the screening in 2000, the apparent incidence increased 12 fold. This is in relation to a large number of microcarcinomas present in the general population that are totally asymptomatic and that will not progress with time; when screening was abandoned in 2014, the incidence decreased by 40% within 3 months. The incidence of high risk thyroid cancers and the thyroid cancer mortality rate did not decrease during the same period of time, demonstrating an overdiagnosis.

To avoid overdiagnosis, the 2015 ATA guidelines recommend to perform a FNA only on solid nodules that are larger than 10 mm in diameter. When the diagnosis of mPTC has been made by FNA, overtreatment should be avoided: active follow-up with surgery at the time of progression (that occurred after a follow up of 10 years in only 14% of cases) may be proposed to patients over 65 years of age, or even to younger patients who do not want to be operated on immediately, when there are no detectable

suspicious lymph nodes at neck ultrasonography, and when the thyroid nodule is not close to the posterior thyroid capsule. If surgery is decided for an isolated mPTC, a lobectomy is performed. There is no need for prophylactic lymph node dissection and no need for post-operative 131-I administration.

## Histological classification

Papillary thyroid carcinoma is the most frequent histological subtype of thyroid cancer and is subdivided in the classical PTC, the most frequent and several variants, including the follicular variant (FVPTC) that represents 20-30% of cases. FVPTC may be totally encapsulated or may present with invasion of the capsule and/or vessels. The encapsulated follicular variant that was recently renamed Non Invasive Follicular Tumor with Papillary-Like Nuclear Features (NIFPT), has a very small (if any) risk of recurrence and is no more named cancer: when FNA shows some nuclear papillary features, it will lead to surgery that is limited to a lobectomy; there is no need for completion of thyroidectomy and for post-operative administration of 131-I.

## Prognostic classification

The TNM (Tumor, Node, Metastases) classification indicates based on the age of the patient at diagnosis and, from the extent of the disease, the risk of thyroid cancer related death.

Two concepts have been added in the 2009 and 2015 ATA guidelines: one is the risk stratification of recurrence that is much more frequent than cancer related death. It takes into account the histology, the BRAF mutation status, the extent of the disease including the size and local extent of the primary thyroid tumor and of lymph node involvement (number and size of lymph node metastases and presence of tumor extension beyond the thyroid capsule). Patients are subdivided into three groups with a low (<5%), intermediate, or high (>20%) risk of recurrence. Age is not taken into account.

The other one is the dynamic risk assessment: at each step of the follow-up, starting with the first work up with serum Tg determination in

*(continued on page 14)*

the absence of serum anti-Tg antibodies and neck ultrasonography, patients are classified into one of 4 subgroups: excellent response, when there is no evidence of disease, biochemical incomplete response when serum Tg remains detectable but in the absence of any structural abnormality, structural incomplete response when imaging reveals some structural abnormalities and indeterminate response. The majority of patients with biochemical incomplete response or with indeterminate response will achieve an excellent response during the subsequent follow-up without any further treatment. Only patients with structural incomplete response may die from thyroid cancer, and obviously these patients may require further treatments. The initial prognosis is revised at each step according to these follow-up data.

### Low risk thyroid cancer: initial treatment and follow-up

The initial treatment of low risk thyroid cancer should not induce any significant morbidity. There is a large consensus for performing a lobectomy for mPTC in the absence of lymph node metastases on pre-operative neck ultrasonography. Lobectomy is also advocated by the 2015 ATA Guidelines for papillary cancer larger than 10 mm when there is no evidence of extension beyond the thyroid capsule and of lymph node metastases, and when the contralateral lobe appears normal at neck ultrasonography. A total thyroidectomy is performed in the other patients and in those who have to be treated post-operatively with 131-I.

Therapeutic lymph node dissection is performed in case of known lymph node involvement. However, prophylactic lymph node dissection of the central compartment in patients with no evidence of lymph node involvement is usually not advocated in low risk patients.

There is no evidence that post-operative administration of 131-I may be beneficial in low risk patients: the risk of recurrence is by definition very low (<3%) and there is no prospective data demonstrating that it may be reduced by post operative 131-I administration: therefore, it is not indicated in mPTC, and is not routinely indicated in low risk patients in particular when post-operative serum Tg is low or undetectable and post-operative neck ultrasonography does not

show any evidence of residual disease. When it is indicated, it should consist in the administration of 1.1 GBq 131-I following stimulation with rhTSH.

In all thyroid cancer patients, follow-up is based on serum Tg determination, preferably using a sensitive method and on neck ultrasonography. After a total thyroidectomy, low risk thyroid cancer patients are treated with l-thyroxine with the objective to maintain the serum TSH within the normal range. Serum TSH and Tg are measured once a year. Serum Tg will become undetectable in the vast majority of patients; when serum Tg is detectable, it will remain at a low level and will not increase with time.

Following a lobectomy, the same protocol of follow-up may be applied. In very low risk patients, it may be not necessary to give any l-thyroxine treatment, when the serum TSH remains in the normal range. Serum Tg may remain detectable at a low level and will not increase with time.

In low risk patients, most of the few recurrences occur during the first years of follow up and low risk patients may not require a follow-up by a specialized centre after 5 years without any event.

### Conclusion

These 2015 ATA guidelines are aimed to reduce overdiagnosis and overtreatment of low risk thyroid cancer patients. This will limit the cost of treatment and its morbidity and will permit patients to enjoy a normal quality of life for decades. There is still a need for prospective randomized trials to provide new evidence that diagnosis, treatment and follow-up of these patients may be even less aggressive.

### References:

Haugen BR, Alexander EK, Bible KC, Doherty GM, Mandel SJ, Nikiforov YE, Pacini F, Randolph GW, Sawka AM, Schlumberger M, Schuff K, Sherman SI, Sosa JA, Steward DL, Tuttle M, Wartofsky L, the American Thyroid Association (ATA) Guidelines Taskforce on Thyroid Nodules and Differentiated Thyroid Cancer. 2015 American Thyroid Association Management Guidelines for adult Patients with Thyroid Nodules and Differentiated Thyroid Cancer. *Thyroid* 2016; 26: 1-133.

# Why are we ignoring the most likely cause for the NAPLAN test results not improving?

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 THE AUSTRALIAN THYROID FOUNDATION

**NAPLAN – “National Assessment Program - Literacy and Numeracy Testing”, undertaken annually by students in years 3, 5, 7 and 9 throughout Australia.**

Here we go again. It is NAPLAN reporting time. Despite great expectations, NAPLAN 2015 results have “flatlined” according to the experts and standards have not improved significantly since NAPLAN testing was introduced 8 years ago. Some authorities have even argued that the NAPLAN testing standards have been dumbed down and the underlying problem is worse than generally appreciated. When considered in conjunction with the comparatively poor performance of our children internationally in the “Progress in International Reading Literacy Study” (PIRLS) and the “Trends in International Mathematics and Science Study” (TIMSS), the NAPLAN results raise serious concerns about the level of educational standards and possibly intellectual capital of current and future generations of Australians. Will Australian society and our economy struggle to compete in the burgeoning Asia Pacific region in the years to come.

So what is the underlying cause of the problem uncovered by NAPLAN testing? Every year we hear the same old opinions and commentaries trotted out as the reasons for lack of improvement, with little or no evidence to support them. First in the firing line, according to the Co-chair of the National Curriculum Review, are the teachers; accused of being poorly trained and poorly mentored and incapable of producing the results we all want to see. Second, the curriculum is said to be not academically based or rigorous enough. Third, school facilities are often substandard with class sizes being too large and classrooms being too small and too noisy.

Finally, in addition to several other theories, parents are also asked to take some blame for the poor performances of their offspring, but not being told how to improve their children’s performance. So it goes on year after year without much change,

leaving some of us who are not involved in school based education to ask is there some other yet unidentified cause? Are we overlooking a more fundamental, underlying problem potentially affecting most or all of our children? Could it be that environmental factors interacting adversely with early biological brain development processes are preventing the brains of our children from fully expressing their genetic potential? One possible cause that stands out for which we have sound, experimental scientific evidence is dietary iodine deficiency impairing maternal and foetal thyroid function. Yes, something as simple as that.

The World Health Organisation says that environmental iodine deficiency is the commonest global cause of impaired brain development resulting in loss of IQ. There is abundant scientific evidence from studies undertaken in developing countries that even mild iodine deficiency occurring during pregnancy can cause impaired brain function in the children born to these mothers. While these intellectual deficits cannot be reversed, they can be made worse by iodine deficiency persisting during childhood when the human brain continues to develop and mature. Population studies of women and children in Australia have shown mild iodine deficiency has been widespread for several decades creating the conditions for adverse effects on the developing brains of children born in this country. So, where is the evidence for this effect on brain function and IQ in Australia? In recently reported studies from the Menzies Institute in Hobart, their researchers found the NAPLAN results of nine year old children born to mildly iodine deficient Tasmanian mothers were around 10% poorer in spelling, grammar and general English-literacy performance, compared with the children born to mothers who were not iodine deficient during pregnancy. This is not an isolated finding, as similar studies recently performed in the UK have documented lower IQ levels in children of mothers who were mildly iodine deficient during pregnancy. These adverse outcomes highlight the crucial role of an adequate iodine intake in mothers and babies to ensure adequate thyroid function for optimal brain development.

*(continued on page 16)*

# The Thyroid Jigsaw

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THE AUSTRALIAN THYROID FOUNDATION

To ensure you receive a proper diagnosis, it is essential for your doctor to order all of the following pathology tests and a thyroid ultrasound. Without all of these tests, you may not be given a proper diagnosis. Therefore The Thyroid Jigsaw may be missing one of the important pieces!

PATHOLOGY	Usual Normal Range	Best Result
TSH - Thyroid Stimulating Hormone	0.5 - 4.00	Around 1.00
T4 - Thyroxine Level	10 - 20	High End of Normal Range
T3 - Triiodothyronine	4 - 8	Exactly in the middle of the range
Thyroid Antibodies - TPO & TGO		Diagnosis of Thyroid Autoimmune Disease, either Graves' and/or Hashimoto's Diseases

**\*\*\* REMEMBER! It is Not The Fact Your Thyroid Pathology Result Sits In The Normal Reference Range... but WHERE Your Result Sits In The Normal Range! \*\*\***

**PLEASE NOTE:** Reference ranges for children and pregnant women may vary from the normal adult reference range. Laboratory reference ranges can vary. Always use the reference range as your

guide in regard to the ATF recommendations and consult your thyroid treating doctor. **THYROID ULTRASOUND** - An ultrasound of the thyroid shows the size, shape and texture of the thyroid gland and if you have nodules. This test is as important as all the pathology tests. So if you have an enlargement of your thyroid gland or discomfort in your neck, a cough, or have trouble speaking or breathing, please ensure your doctor requests a thyroid ultrasound.

**ADDITIONAL SCAN: Thyroid CT Scan** - A Thyroid CT Scan is a Nuclear Medicine Scan. A small amount of radioactive iodine (RAI) contrast solution is injected into the patient's arm before the scan begins. The scan will show the uptake of the RAI Iodine through the Thyroid Gland.

**PLEASE NOTE:** If your treating doctor has requested a Thyroid CT Scan and you have been diagnosed with Hyperthyroidism and/or a Heart Disorder, please be aware of related consequences from the RAI Contrast Solution used for CT Scans, MRI Scans and other Nuclear or Radiography Testing.

REF: PROFESSOR JIM STOCKIGT – ATF THYROID NEWS NO 13, SEPT 1999 – IODINE CONTRAST SOLUTIONS – USED IN CT SCANS AND OTHER X-RAYS

## NAPLAN test results... (continued from page 15)

In 2009, Commonwealth, State and Territory governments responded to the health threats posed through the reemergence of iodine deficiency in Australia by mandating that all salt used in the baking of bread be iodised. The National Health and Medical Research Council acknowledged that this initiative, while a positive step, would not be enough to correct iodine deficiency in pregnant women in Australia so it went on to recommend iodine supplementation for pregnant women. Unfortunately, iodine supplementation rates are only around 50% for pregnant women in this country so we can calculate that theoretically 150,000 pregnancies are at risk annually of not getting enough iodine, putting the brains of these babies at risk of developmental disorders. We have recent data from studies on young

Aboriginal women in the Northern Territory that the problem is most marked in those living in remote regions. Nothing has been done about it. Until we correct this public health problem it is unlikely that we will see progress in educational performance of Australian children and we will continue to speculate on why NAPLAN test results are not improving and why we are falling behind our Asian neighbours. Most importantly we are denying these children their basic human rights to develop their brains to their full genetic potential. It is a national disgrace that needs urgent corrective action.





# The Thyroid Hormone Replacement for Subclinical Hypo-Thyroidism Trial (TRUST)

YVONNE ANDERSSON LAKWIJK



## What is the trust-project?

Right now, there is no common way to treat people with subclinical hypothyroidism. Researchers hope to find it with the TRUST study. TRUST researchers will follow 3,000 older people over a five year period in an attempt to better understand how to treat people who suffer from subclinical hypothyroidism. Half of the subjects will be treated with a hormone replacement drug, thyroxine, while the other half will be given a placebo; both groups will then be monitored to evaluate how they respond to the treatments.

The organisation funding the research is the European Union. The team conducting the research in Scotland is from the University of Glasgow; this research is in collaboration with Leiden University Medical Centre in the Netherlands, Cork in Ireland, and University of Berne in Switzerland. We are also collaborating with thyroid experts from the University of California in the USA.

## Who has reviewed the study?

The research project has been reviewed by, and received approval from the following;

- The European Union grant reviewers (includes ethical review).
- The Scottish Multicentre Research Ethics Committee (MREC A).
- Thyroid Federation International, the umbrella organisation for patient support groups for those with thyroid disorders. It aims to work for the benefit of those affected by thyroid disorders throughout Europe and the world.

## Update

The recruiting of participants started in 2012 and was finished in December 2015. The last patient will leave the study in November 2016.

The results of the main part of the research should be available within 6 months after completing the study, and it is expected the primary publication will be within 12 months.

The next meeting will be held in Glasgow



in January 2017. We are still embroiled in that awkward period of the grant with lots of work to do to finish the study, and endless admin with the EU - however we are making progress. The formal launch of the results will not be until April 2017.

Provision of medicines for the study is supported by Merck KGaA.

I hope the results of this study will give input for new international guidelines to treat people that suffer from subclinical hypothyroidism. It can contribute to the health of millions all over the world.



ITAW brochure

## The Australian Thyroid Foundation – Thyroid Awareness Month

BEVERLEY GARSIDE  
CHIEF EXECUTIVE OFFICER  
THE AUSTRALIAN THYROID FOUNDATION LTD.  
[HTTP://WWW.THYROIDFOUNDATION.ORG.AU](http://www.thyroidfoundation.org.au)

The Australian Thyroid Foundation applied to the Australian Federal Government to be included on the Australian National Health Calendar for the month of May each year. May would be known as 'Thyroid Awareness Month.' The request was granted and the ATF organised our very first Thyroid Awareness Month campaign.

### May includes the following ATF messaging:

Thyroid and Pregnancy – Australia's Mother's Day - which covers the importance of women of childbearing age taking a pregnancy supplement including at least 150 mcgs of iodine and the importance of ensuring their thyroid hormone levels are adequate during pregnancy and breastfeeding.

World Thyroid Day and International Thyroid Awareness Week – connecting to TFI messaging on an annual basis.



Through the support of the ATF Media Company, Ogilvy PR Health, a series of 4 audio announcements were produced to be heard on radio stations nationally. The announcement can also be heard on the ATF website [www.thyroidfoundation.org.au](http://www.thyroidfoundation.org.au) These announcements covered:

Hypothyroidism, Hyperthyroidism, Thyroid Cancer and Thyroid and Pregnancy.

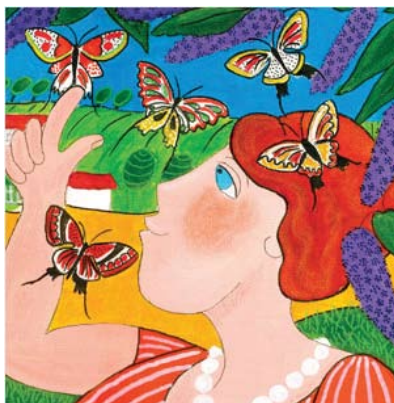
The month was a huge success, also including radio interviews, online articles and print media. The ATF intend to expand Thyroid Awareness Month each year to promote the importance of Good Thyroid Health.'

## World Thyroid Day in Denmark

BENTE LASSERRE, VICE-PRESIDENT OF THYREOIDEA  
LANDSFORENINGEN  
[WWW.THYREOIDEA.DK](http://WWW.THYREOIDEA.DK)

To celebrate World Thyroid Day in Denmark and the theme of 2016, Thyroid Disorders in Children, we held a patient forum for children with thyroid disease and their parents. It was a very good meeting with a lot of information and answers from Dorte Hansen MD, pediatrician at Odense University Hospital, and plenty of time to talk with others with the same disease.

**THYREOIDEA**  
LANDSFORENINGEN



*One of the participants was Marie, 4 months old. She is so adorable.*



# International Thyroid Awareness Week 2016 – Worldwide

The ITAW has been organized by TFI since 2009, in cooperation with Merck. This year's campaign was called **"Catching the butterflies: Spotting the symptoms of thyroid disorders in children."**

The aim was to raise awareness of thyroid disorders in children. The website [www.thyroidweek.com](http://www.thyroidweek.com) provides information in 12 languages, videos and brochures to download. A little booklet for children tells the story of "Hypo" and "Hyper", 2 little butterflies.

In 2016, the ITAW campaign was rolled out in 33 countries.

A total of 501 pieces of coverage were secured globally, with an estimated reach of over 20 million (media coverage in TV, print, radio, online).

Many events were organized, in many different countries: Screening and TSH test events, informational meetings for patients, scientific meetings with physicians, balloon events, art competition ...

## A short report from Algeria:

"We had many activities going on at our booth: a clown / magician engaged with the children, colouring workshop (butterflies), you could take a thyroid quiz, watch the ITAW butterfly video, have a butterfly drawn on your face with make-up, have your picture taken in front of a personalized ITAW wall, eat butterfly cookies, etc. "



Algeria



Tunisia



Indonesia

**May 22 to 28, 2017**

**9th International  
Thyroid Awareness Week**

[www.thyroidweek.com](http://www.thyroidweek.com)  
[www.thyroidweek.org](http://www.thyroidweek.org)





# International Thyroid Awareness Week in India

The Thyroid Federation of India in association with the Thyroid Cancer Group held an educational and awareness lecture on World Thyroid day on May 25th, 2016. The topic for the World Thyroid Day was a lecture on "Refractory DIFFERENTIATED Thyroid Cancer"

The session started with a lecture on TSH Recombinant Technology in DTC by Dr M S Senthil Kumar, President of Thyroid Federation of India. This was followed by a presentation on 'Refractory Differentiated Thyroid Cancer-Management and Implementation of guidelines related to India for a consensus based approach'. The Chairpersons for the session were Prof. Anitha and Prof. K. Kuberan. The panelists were a good mix from various departments, i.e. Dr Mahesh and Dr Prasanna from Radiation Oncology, Dr Satish Nath and Dr Prabhu from Nuclear Medicine, Dr Shantha from Pathology, and Dr Ramkumar representing General Surgery. It is important to include different facets of the Medical fraternity for developing consensus guidelines. This event was made possible because of the importance given to Thyroid World Day May 25th and International Thyroid Week 2016. The intent of the consensus guidelines is in the best interest of patients and helps the medical fraternity to adhere to some agreed consensus. This event should help in establishing a white paper on the consensus that can be published.

## About Thyroid Federation of India's Mission and Vision

- Thyroid help is founded to assist the detection of various thyroid disorders among the vast multiethnic states of India.

- Thyroid help will initiate common goals towards management of thyroid disorders in the Indian subcontinent.
- Thyroid help intends to carry out awareness programs with the public, supportive programs with patient groups, and thyroid cancer survivors.
- Thyroid help will formulate treatment guidelines involving thyroid specialists and experts in the field of endocrine surgery and endocrinology.
- Thyroid help will provide a forum for discussion involving social media, institutions, corporations, patient groups and the general public.
- Thyroid help will facilitate the process of policy making in various thyroid disorders involving bureaucracy, administration and governing bodies of the Indian government and the respective state government.
- Thyroid help will encourage youth, keen to volunteer, who can apply to become Members of the Federation for a common cause.

FOUNDER PRESIDENT: DR M.S.SENTHIL KUMAR, VICE PRESIDENT: DR.JAYARAJ, SECRETARY: DR PRABAKAR

JOINT SECRETARY: DR RAJAN, TREASURER: SARITA

EXECUTIVE COUNCIL MEMBERS: DR.REPUBLICA, MRS JAYA, DR. KAMALARATHNAM, REVATHY RAJAGOPAL, DR. RASAPPAN, ER MEERA

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## ITAW 2016 – Worldwide... (continued from page 19)



*Gulf region.*



*Portugal*

# The Thyroid Institute may be considered the best accessible public information on thyroid disease in Brazil

GERALDO MEDEIROS-NETO AND EDUARDO K. TOMIMORI, MDS

The Thyroid Institute was founded in December 2001, with the main objective to provide general information on thyroid diseases.

In order to comply with this objective, we have provided monthly new information about treatment and care of patients with nodules or presenting other different thyroid diseases, such as hyperthyroidism, low thyroid function, benign nodules, and chronic thyroiditis. Hypothyroidism, nodules, multinodular goiter, and thyroid cancer are the most common thyroid diseases that are found in Brazilian population.

Short articles under the topics above are consulted monthly by people around the world on our website ([www.indatir.org.br](http://www.indatir.org.br)) and our Facebook. There are an increasing number of visitors over the past years, reaching on May 2016, the impressive number of 60,466 visitors as compared to 40,999 in July 2015. Aside from this way to spread information, we have personal questions about thyroid disease and treatment addressed to our team of experts which tries to answer them as close as possible on treatment, surgery and side effects from drugs and, quite often, some way to avoid surgery. This kind of

personal information is performed under total control of the medical code of ethics.

Therefore, we try to maintain a precise limit of information to the patient without crossing the limit of ethics. During 2015, we had the XV International Thyroid Congress in Orlando, FL. In this meeting, the Thyroid Institute was represented by our Secretary, Eduardo Tomimori, who was pleased to make a short comment on its activities.

We are proud to observe the continuous increase of interest in thyroid diseases and treatment, and scientific interest in thyroid physiology and pathology. It seems, based on general information from the public, that the thyroid gland is the most popular endocrine system.

The Thyroid Institute plans to continue educating the general public about the need for iodine supplementation during pregnancy, the constant need of neonatal testing for congenital hypothyroidism, and the need for surgical treatment of confirmed thyroid cancer.

Looking forward to participating in the international thyroid meetings, bringing our own experience in South America,



# Patient survey: Quality of life after thyroidectomy



BEATE BARTÈS, PRESIDENT  
ASSOCIATION VIVRE SANS THYROÏDE

Quality of Life studies on thyroid patients are rare, and most of them concern cancer or hypothyroidism. The French patient association “Vivre sans Thyroïde” decided to investigate the quality of life of patients who underwent thyroid surgery, and to compare the results between the group diagnosed with thyroid cancer, and those who suffered from other thyroid dysfunctions (benign nodules, goiter, hyperthyroidism).

The survey took place in spring 2015, via an online questionnaire, combining a general QoL questionnaire (MOS SF-36) and a questionnaire specially aimed at thyroid disease, developed by our association and tested among our volunteers. Participants were enrolled via our website and social media. The MOS SF-36 scores were compared to the reference values for the general population, and two subgroups (cancer vs. other diseases) were compared to each other.

1142 patients from France participated in the survey (90% women, 10% men). The average age was 45 years (18 to 84 years). 42% had cancer, 58% had a benign pathology. The average QoL score was 59 (which is nearly 10 points below the QoL score of the general population), with particularly

low scores regarding emotional well-being, vitality and social functioning.

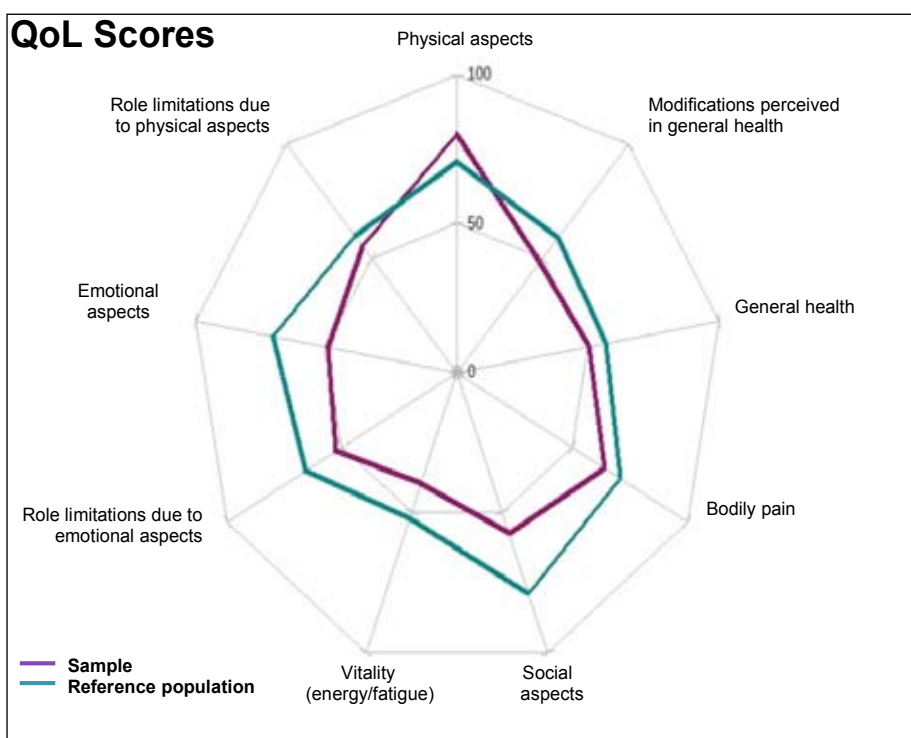
Factors influencing the quality of life after thyroid surgery: The number of surgeries, the cancer diagnosis, the need for a radioiodine treatment and the announcement of a “good-to-have” cancer had no significant influence on the QoL scores, whereas we noticed an important difference related to emotional support, satisfactory information about the disease and its treatment and the presence of side-effects after the surgery. Weight gain also significantly diminished the QoL score.

## Conclusion

The quality of life after thyroid surgery in our panel is inferior to the QoL of the general population, even if the difference is not significant. The patients are particularly affected in all aspects regarding emotional well-being, social functioning and vitality. For physical aspects and general health status, the QoL scores are close to those of the general population.

The type of disease had no influence on the quality of life: the results in the «cancer» and «no cancer» group were quite similar. The survey pointed out that the quality of life after thyroid surgery is significantly influenced by the presence of side effects, by the emotional support from family and friends, by a possible (and in some cases considerable) weight-gain and by the quality of information received before and after surgery.

Total thyroidectomy is not a “benign” surgery, and a more conservative approach could be beneficial for the patients. Our survey shows that today’s patients are active, longing for information, and want to be involved in decision-taking and in the treatment of their disease: 1329 patients participated in the survey, in France but also on all other continents.



# Patient/Survivor Survey – Thyroid Cancer Journey and QoL



HARALD RIMMELE, BUNDESVERBAND SCHILDDRÜSENKREBS  
"OHNE SCHILDDRÜSE LEBEN" E.V., GERMANY: [WWW.SD-KREBS.DE](http://WWW.SD-KREBS.DE)

BEATE BARTÈS, ASSOCIATION „VIVRE SANS THYROÏDE“,  
FRANCE : [WWW.FORUM-THYROÏDE.NET](http://WWW.FORUM-THYROÏDE.NET)

In 2016, the German and the French patient organization performed a bilingual survey on the cancer journey and the quality of life of thyroid cancer patients. This survey was inspired by the international patient survey done in 2010 by the Thyroid Cancer Alliance ([www.hormones.gr/8432/article/article.html](http://www.hormones.gr/8432/article/article.html)) – we adapted and detailed certain questions and added others.

## Aim

- Evaluate the impact of a thyroid cancer diagnosis on the patient’s quality of life
- Identify differences between treatment protocols
- Point out aspects which need to be improved
- Identify changes with regard to the 2010 survey

## Participants

The survey was done via an anonymous online questionnaire, between March and June 2016. Participants: 1217 (85.1% women), recruited via the German and French discussion forums, email newsletters and social media. 50.8% were from Germany, 31.8% from France (other participants came from Austria, Switzerland, Canada, Algeria, Belgium ...). 75.3% had a papillary carcinoma (more than 80% of all cancers were differentiated). 75% of the responders received the diagnosis between the age of 20 and 50 – for more than 80%, this was

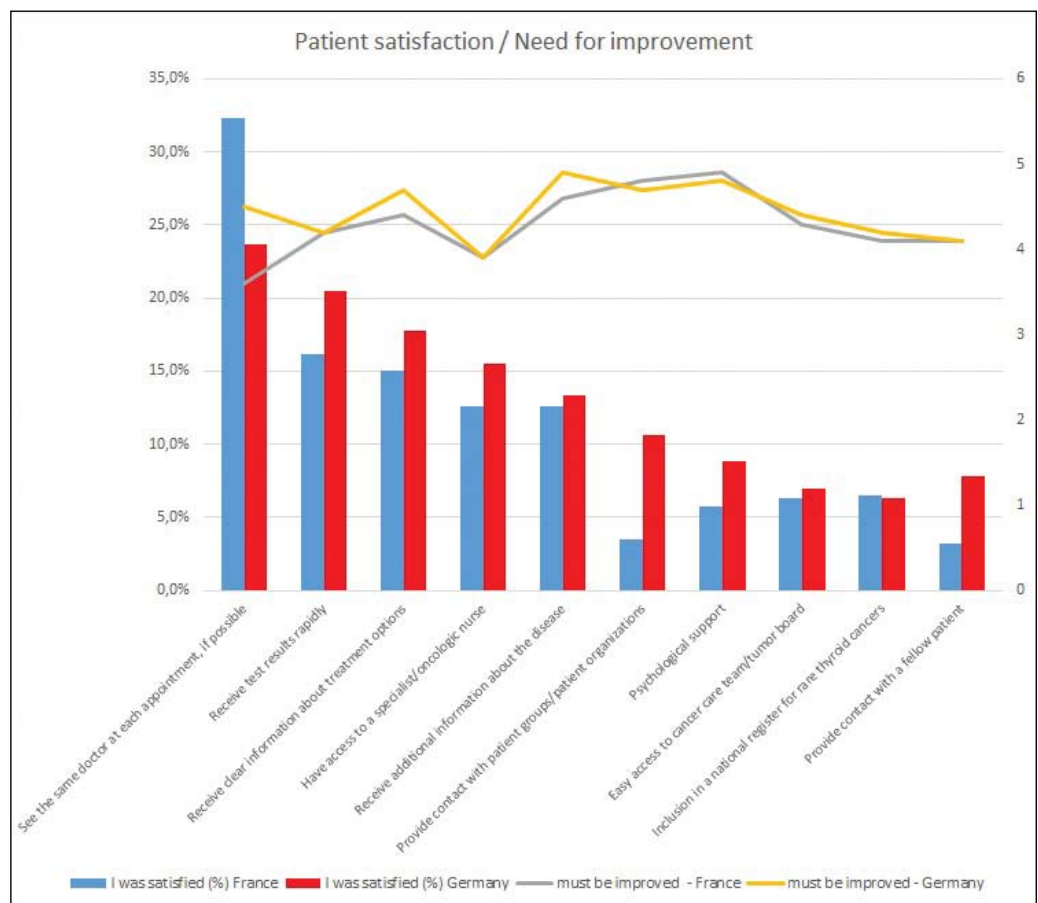
more than 1 year prior to our survey. 72% of the responders indicated to be disease-free. 5.5% have metastases visible on imaging.

## Patients want information!

Only 35% received clear written information on their disease and on treatment options at the time of diagnosis. 80% of all participants indicated that they looked for information on the Internet. The responders indicated that the information provided by patient organizations (printed or via the Internet) was the most useful information they found during their cancer journey.

Disease burden, need for improvement: The most difficult aspect, for most of the participants, was to receive the diagnosis “cancer”. Patients who have their medical appointments always with the same doctor (23.7% G, 32.3% F), and who rapidly receive their test results, are more

*(continued on page 24)*



satisfied. Only a small percentage (3.5% in France, 10.6% in Germany) received information about the existence of patient groups. Patients find it important to always be addressed by the same doctor, and see an important need for “more psychological support” and “more information about the disease”, in all phases of the disease. These needs were already addressed in the TCA survey in 2010 – and are still far from being totally met.

### Quality of life: often treated as a minor matter!

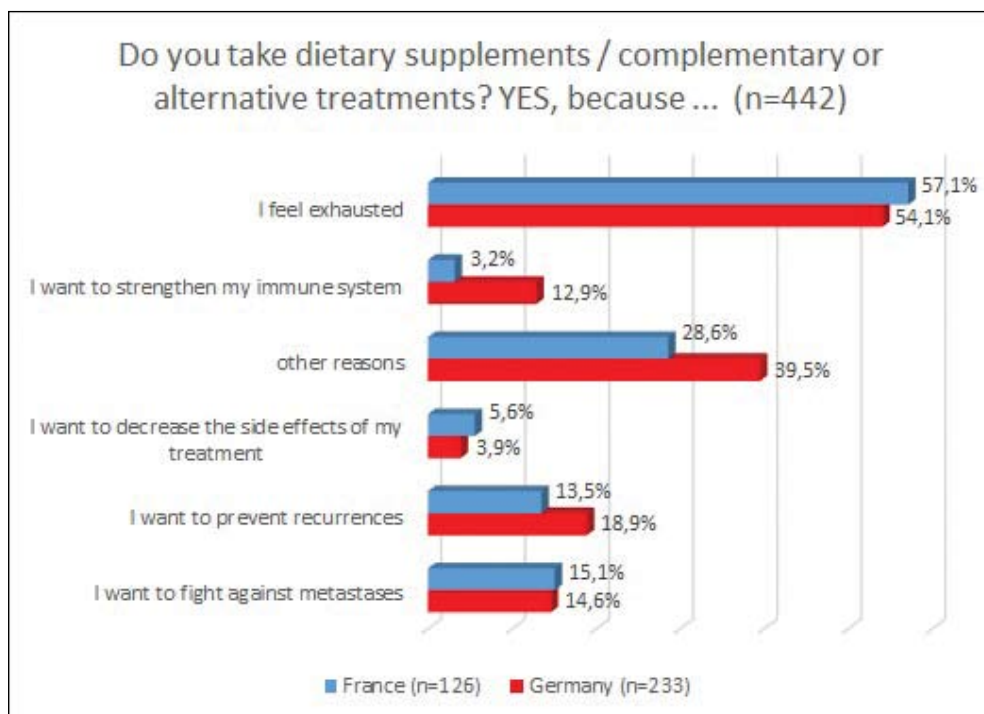
Many thyroid cancer patients complain about a decreased quality of life. One of the indicators is the fact that 37.2% of all responders have changed their hospital/ doctor at least once, and that 19.2% more think about such a change in the near future (1/3rd of these have already changed at least once). The main reasons for this change (or intention to change: value indicated in brackets) are the following: “I don’t feel like I receive competent care” for 32.9% (38.9%), and “my doctor/ former doctor doesn’t care about my quality of life” for 28.9% (50.9%). Another

factor showing that patients do not have the desired quality of life is the important number of patients (36.3%) who take dietary supplements (complementary or alternative treatments) – the main reason for this supplementation is increased fatigue.

### Conclusion

Our survey brought up a huge amount of additional results regarding the details of diagnosis, treatment and follow-up of thyroid cancer patients, pointing out various differences between countries (Germany / France) and between patients treated in non-specialized hospitals vs. patients taken in charge by specialized thyroid cancer centers/networks.

First results have been presented at a doctor-patient workshop during the congress of the German Society of Nuclear Medicine, DGN, in Dresden, April 2016; a poster will be presented at the congress of the French Endocrine Society, SFE, in Bordeaux, in October. Further presentations and publications are planned. The results will also be published on both organizations’ websites.



Reasons for the intake of dietary supplements or alternative treatment (n=442)



# The Dutch Thyroid Association is working hard for advocacy and research!

AUDREY BREIJMAN

The 2016 Thyroid Awareness Week, annually organized by the Dutch Thyroid Association (SON), took place from May 23-28. The large number of volunteers at the conference contributed to making the week a huge success. Attendees were educated about all sorts of things related to thyroid conditions, with additional focus on children with (acquired) thyroid disease. There were also various gatherings throughout the Netherlands and Dr Hanna Bosmans, the prizewinner of the 2016 General Practitioner Conference (Huisartsbeurs), was honored by SON director Rietje Meijer. Additionally there was discussion of the Thyrox shortage which has been an issue in the Netherlands since this past January.

## Thyrox Shortage

On January 13, 2016 it was made known on short notice that Thyrox Duotab would no longer be available. Explaining how the Dutch Thyroid Association responded to this news, Rietje Meijer states that "First we collected a great deal of information and communicated this to our constituency and members. By way of multiple newsletters and updates, including the use of social media, we have endeavored to provide as much information as possible to everyone. After the phase of providing information on stock levels, giving advice on transitioning to new medications, and hosting activities for the responsible parties, advocacy has become our first priority. The Dutch Thyroid Association started a petition that has now been signed by over 15,000 people."

"As a patient organization we are thrilled that we have been able to set this topic on the political agenda with all the help from our supporters. Our politicians take medicine shortages seriously and are working hard to take various measures in the fields of medication research and policy among others," says Rietje Meijer.

The initial concern has abated. Patients and interested parties have been informed and have started transitioning to another brand. For some patients, this will come with adverse effects. The



Dutch Thyroid Association is there to help and support them, and for this to happen funding has been set aside by the Ministry of Public Health, Welfare and Sport for a temporary support and information center: the Thyrox Shortage Support Center (Steunpunt Thyrox Tekort). Additionally the

Dutch government has appropriated funds and initiated research which will look at to what extent and in what way various doses of different brands of thyroid medicine affect patients. The research will be conducted on behalf of the Dutch Thyroid Association and the Dutch Endocrine Society (NVE). Renowned researchers NIVEL and PHARMO will be conducting the study. It is hoped that the results will be presented by the end of 2016.

## Looking back at the 2016 Thyroid Awareness Week

The Thyroid Awareness Week started with a meeting in the week leading up to the 23rd of May. This kickoff was arranged by Dr Paul van Trotsenburg. He treated the audience to an informative and interactive lecture on children and young adults with a thyroid condition. This meeting took place in the Emma Children's Hospital (AMC) in Amsterdam, Dr Paul Trotsenburg's own home base.

During this week dozens of volunteers were out and about in order to disseminate information to parents, children, and other interested parties. Information was presented by volunteers at booths in various hospitals throughout the country. Brochures and cards were displayed and the public was encouraged to make use of special drop-in appointments for more information. As a result, the collaboration between general practitioners, hospitals, and the Dutch Thyroid Association was intensified this week.

"It is great to see that we can depend on the help and work from our volunteers on a national level. They are fully committed to help everyone. We have access to a great deal of brochures which cover all sorts of things relating to thyroid disorders. This information is not just for patients

*(continued on page 26)*

or their friends and family, but is also relevant to others in the medical field, such as general practitioners,” states Rietje Meijer.

For the 2016 Thyroid Awareness week, besides the brochures and other materials already available, there was also information available for specific topics. Various articles from the patient magazine Thyroid were made available, including an article on the moment when young adults switch from seeing their pediatrician to the endocrinologist (an important one!) There were also cards available from Cyberpoli, an online and interactive meeting place for children and young adults with a chronic disease, including thyroid conditions. Visitors could take a look on [www.cyberpoli.nl](http://www.cyberpoli.nl). Additionally there was a special brochure for children provided by pharmaceutical company Merck which was passed out with matching stickers from the Dutch Thyroid Association.



Information booth during Thyroid Awareness Week 2016.

## Pride

There was a lot of activity this year in the Netherlands regarding thyroid issues. By being involved with current issues such as the Thyrox shortage and with their annual Thyroid Awareness Week, the Dutch Thyroid Association can play a significant role for patients and stakeholders. To the question of whether there are other things the association is proud of, Rietje Meijer answers, “We have worked hard to be visible as an organization. Our presence at various conferences such as the national Health and Wellness Fair and General Practitioner Conference, and of course the Thyroid Awareness Week, are good examples of this. We are getting a more and more important role in the thyroid “playing field”. I see the organization as an advocate, a networker, and a connector between various authorities. Within this structure, the patient is supplied with relevant information and can be helped with all sorts of questions

and concerns which we can pass on for them. The fact that we are able to set urgent issues on the political agenda as a patient organization is something that I am proud of.”



Thyroid Awareness Week 2016 took place throughout the Netherlands

## Priorities and the Dutch Thyroid Association in the future

Looking forward, Rietje Meijer says that “We want to give even more access to all of the knowledge we have accumulated and use it to educate our supporters and other players in the field in a proper and timely manner. One of our priorities is to set up and maintain a robust knowledge-based network, which we will do together with our Medical and Scientific Advisory Board (MAR). The MAR will allow us to better inform patients and their families. We would also like to expand our role as patient advocate. That means that we can proactively respond to what is important in an even better way. The board and the management of the Dutch Thyroid Association see this as an important task for the coming period. For that reason, it is very important to use just the right communication and methods. We have noticed that we can’t go without digital media in this day and age. In addition to our ‘physical’ monthly magazine Thyroid, which is still being read with pleasure by our supporters and donors, social media is becoming increasingly important. And that is a priority as well for us.”

## A wish for all

On the last question, “What is your wish for the future?” Rietje Meijer answers “I am already very happy that we are constantly improving in our role as a knowledge-based network,

(continued on page 27)

## Dutch Thyroid Association (continued from page 26)

supporter and advocate. It is also nice to see that a negative development such as the Thyrox shortage can result in something positive, namely solid research into the importance of continuity



Awards ceremony at the General Practitioner Conference, Hanna Bosmans (left) and Rietje Meijer (right).

of medications. High on the agenda for patients is further research into so-called “residual symptoms”. I think that our association, together with international organizations, have to make the case and convince scientists of the importance of their involvement in solving this problem.”

### The Dutch Thyroid Association

The Dutch Thyroid Association advocates for the needs of thyroid patients. Its activities are aimed at the improvement of care and well being for people with thyroid conditions. The Dutch Thyroid Association provides education, telephone support, organizes meetings and informational events, and advances scientific research. The international contact person on behalf of the board of the Dutch Thyroid Association (SON) is board member Marian de Ruijter. Day to day management is performed by director Rietje Meijer.

## ACTIVITIES AND PROJECTS OF THE NATIONAL ORGANIZATIONS

## NORWAY

# The Norwegian Thyroid Federation – 25 years

ANNE KATRINE PAULSEN

Of Norway’s 5 million inhabitants, 215, 000 have a thyroid disease. The Norwegian Thyroid Federation has worked for politicians to recognize the issue, lower the prices on medicine, increase research and put an end to the main focus shown by doctors on the treatment of hypothyroidism. Twenty-five years of targeted work has brought increased awareness. We have 7,000 members and 32 branches across Norway.

In the 1980s, the profiled journalist Per Egil Hegge put the spotlight on the neglect of hypothyroidism. His wife suffered severely, but could not get sufficient help. Hegge wanted to learn and started to dig. He attended lectures for medical students, but was begged to stop asking questions. At the time, there was not one page about thyroid disease in the students’ books. Hegge wrote the book “Please do not ask questions” about the disease of his wife, a book in which one could find helpful information to get better. This book led to a large group of women realizing that there was a specific reason for lacking energy, gaining weight, problems with concentration, depression: thyroid disease!



A handful of women decided to get together and establish our patient organization. The kick-off meeting took place on 18th December 1990. The main activity in the federation has always been to educate about the disease and its challenges, and to get the medical profession, media and politicians to research and recognize this widespread disease. The effort resulted in media attention, and the phones started to ring – people wanted to join us and learn more.

Informing and helping members has always been our main objective. We organized seminars, which were open to all members. The aim was to spread knowledge about various aspects of the disease, medication, and treatment; we organized workshops on peer support and organizational knowledge. The federation grew, and we established more and more local branches across Norway.

We established ties with other organizations, to get stronger and more powerful.

The organization was contacted by people with other thyroid diagnoses than

(continued on page 28)

## Norwegian Thyroid Federation (continued from page 27)

hypothyroidism: those with hyperthyroid disease, those who have had surgery – and by youth, parents, and men. The federation started to focus on peer work, and held classes for those who wanted to do voluntary peer work. At the time we started, we didn't have a proper office, but as more members joined and we put ads in local papers to summon people on every mountain and in every fjord, things started to happen. In 2000 we printed our first edition of our magazine Thyra, where we announced events – urban and rural. In 2002 we rented a separate office space for our employees. Membership activities increased significantly. Thyra became increasingly professional as we put together a small advice team, endocrinologists and general practitioners with a special interest in thyroid disease. They occasionally visit morning television shows, for instance together with a thyroid patient they have helped, and when we later put the TV



interview on our own Facebook page, we monitor a huge interest for this kind of information.

A great day for The Norwegian Thyroid Federation, was when our national thyroid day became international. The decision was made by Thyroid Federation International (TFI) in Leipzig in August 2007, on proposal from us.

Last year Stoffskifteforbundet – The Norwegian Thyroid Federation – celebrated 25 years, our magazine Thyra 20 years. We have 8000 paying members, 8000 friends on a very active Facebook page, and we have established

a useful internet page and intranet. Once a year, we hold seminars for our various patient groups, and in the autumn each year we organize trips to warmer latitudes. This year, there are about 45 of us who'll enjoy Mallorca in October. May the future be sunny for all our members.

## ACTIVITIES AND PROJECTS OF THE NATIONAL ORGANIZATIONS

## CANADA

# TFC: New Ideas – New People – What a difference a day makes.

MABEL MILLER, PRESIDENT

In 2015 The Thyroid Foundation of Canada celebrated 35 years as the first organization in the world supporting Thyroid patients. We did great things and excelled in being there for thyroid patients who so desperately needed assistance in managing their condition. In later years, with times changing it became clear we were not getting the support to do what we needed to do and didn't seem to be attracting others to become part of the National Board. In 2016, it seemed to be a turning point, so we embarked on a more outgoing approach and plea for others to get involved. Thankfully we were successful and the results were way above what was expected or hoped for. We now have a very vibrant group of board members who have the interest and the skills to push ahead with getting things done that are so badly needed for thyroid patients. We are challenged yet we are excited about working together and moving forward with new ideas,

a new look, new methods of communications, a better link with the medical community and finding the right fit to support us financially. A lesson learned – never give up, just when we thought all hope was lost, we turned a corner and found some answers to our cry for help – for others to get involved. We can never give up on finding ways to best help and support those with thyroid disease who desperately need us. We must never lose sight of why in 1980 Diana Meltzer Abramsky forged ahead in starting something to support thyroid patients. In 1990 Thyroid Federation International was formed and we now see thyroid patients all over the world supported by many such organizations so they can too benefit in being able to manage their conditions better. We look forward to working with all who have the same interests in mind.

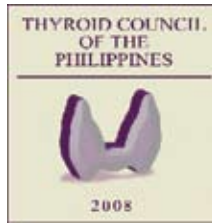


Thyroid Foundation of Canada

La Fondation canadienne de la Thyroïde

## The TCP joins TFI

The Thyroid Council of the Philippines (TCP) was established in 2008 as an umbrella organization of 10 medical societies, a few allied professional organizations (e.g. nurses, midwives and nutritionists), national governmental agencies (NGA) and NGOs. Teofilo O.L. San Luis is the current Chair of TCP.



The TCP spearheads 3 activities throughout the year: **Goiter Awareness Week** (every 4th week of January), **World Thyroid Day** (May 25) and **Thyroid Cancer Awareness Week** (every 4th week of September).



Mini-lecture and lay forum with Dr T. O.L. San Luis Jr. (for TCP), Dr Michael Villa (for the Philippine Society of Endocrinology, Diabetes & Metabolism, PSEDM) and Dr Wenceslao Llauderer (for the Philippine Thyroid Association, PTA).



Adult patient consultation and neck palpation by Dr Michelle Ogbac of PTA



Venue at the GF of Fisher Mall fully decorated by butterfly-shaped buntings.

In 2016, World Thyroid Day was celebrated on Saturday, May 28, at the Fisher Mall in Quezon City, in cooperation with Merck, following the theme "Thyroid Diseases in Children". After mini-lectures and a lay forum, adult patient consultations and neck palpations were carried out by invited physicians. There were also a children's artwork competition and colouring all sizes and shapes of butterflies. There were many children who took home balloons and coloring books.



Children's Artwork Competition (Drawing & Coloring Categories) with prizes for the winners.

## GDATF 2015-16 Highlights

The Graves' Disease & Thyroid Foundation celebrated our 25th anniversary in 2015, and we have no plans to slow down! Following are some highlights from 2015-2016:



In May 2015, two key physician organizations, the American Association of Clinical Endocrinologists (aace.com) and the American Association of Endocrine Surgeons (endocrinesurgery.org) joined forces and hosted their annual meetings on back-to-back dates in Nashville, TN. On Saturday, May 17th, the GDATF hosted a patient outreach meeting with endocrine surgeon Dr. Dawn Elfenbein from UCLA Irvine on hand to answer patient questions.

In October 2015, the American Thyroid Association (www.thyroid.org) hosted the 2015 International Thyroid Congress (ITC) in Orlando, FL. The ITC is a collaborative meeting held every fifth year, with hosting duties rotating among the four world thyroid associations: ATA, Asia-Oceania Thyroid Association, European Thyroid Association, and Latin American Thyroid Society.

Prior to the formal start of the meeting, GDATF Founder and Chair Emeritus, Nancy Hord Patterson, Ph.D., represented the Foundation at the annual meeting of the Thyroid Federation International. The ITC then kicked off with a community forum co-hosted by the ATA and the Alliance for Patient Education, including the GDATF. Many thanks to the physicians who donated their time to attend the event, especially

Dr. James Hennessey, Associate Professor of Medicine at Beth Israel Deaconess Medical Center, for

answering questions at the Graves' disease table! Research highlights presented at the ITC included:

**Thyroid Dysfunction and Pregnancy:** In the "Emerging Strategies in Pregnancy Screening" symposium, Dr. Weiping Teng discussed the success of China's universal screening programs for thyroid dysfunction in pregnancy. The U.S. lags behind the rest of the developed world in this area, with doctors and researchers split on the value of universal screening. Dr. Brian N. Casey noted that the U.S.-based endocrine associations only recommend TSH screening in specific situations, which could miss up to 65% of undiagnosed cases. In the symposium "Clinical Utility of Antithyroid Antibody Measurements", Dr. Alex S. Stagnaro-Green noted that, "Pregnancy is a very dynamic state for someone with autoimmune thyroid disease; it's a stress test for the thyroid. Dr. Stagnaro stated that the risk of miscarriage is elevated with TSH levels of 4.5-10, and is even higher with TSH levels exceeding 10. Dr. Stagnaro-Green explained that studies have shown that adding T4 therapy can reduce the risk of miscarriage and preterm births in women who are antibody positive, but have normal thyroid levels. A discussion/debate on "Minimizing Birth Defects After the Use of Anti-Thyroid Drugs" from Dr. Jorge H. Mestman and Dr. Bijay Vaidya discussed the risks and benefits of anti-thyroid drug use during pregnancy. PTU is currently considered the preferred medication during the first trimester, as methimazole has been associated with a higher risk of birth defects. However, recent research has shown that PTU is also linked to birth defects, although the risk is less than that with methimazole and the effects tend to be less serious.

**Long-Term use of Anti-Thyroid Drugs (ATDs):** Dr. Stig Andersen and Dr. Douglas S. Ross participated in a discussion/debate on this issue. Current medical guidance recommends a course of 12-18 months of medication, but notes that longer-term therapy "may be considered in patients not in remission who prefer this approach."<sup>1</sup> Some doctors cite side effects as a reason to avoid long-term use of ATDs, although the presentation noted that more serious side effects, such as liver problems and agranulocytosis (a severe reduction in white blood cells), almost always occur early in therapy. One exception is with the use of the anti-

(continued on page 31)



Kimberly Dorris, Executive Director, GDATF (USA); Beate Bartes, President (and Butterfly) Vivre Sans Thyroïde (France) and Dr. Nancy Hord Patterson, Founder, Graves' Disease Foundation (USA) at the ITC in Orlando, Florida, USA, October 2015.

thyroid drug PTU, which comes with an increased risk of vasculitis (a dangerous inflammation of blood vessels) the longer that therapy continues, particularly with increased doses.

**Thyroid Eye Disease:** Dr. Mario G. Salvi and Dr. Marius N. Stan participated in a discussion/debate on "Rituximab Therapy for Graves' Orbitopathy". Both doctors have been involved in studies on the use of Rituximab with markedly different results. Dr. Stan's research showed no benefit, but Dr. Salvi's group showed improvement versus IV steroid therapy. Differences in the study groups could be responsible for the differing results; the U.S.-based group was older and had higher antibody levels; the Italian group had more smokers and tended to have a more recent diagnosis. Further studies are needed to assess Rituximab's effectiveness.

The GDATF also attended a special seminar on thyroid antibodies hosted by Quidel and closed out 2015 in Las Vegas in November, where we exhibited at the annual symposium of the American Society of Ophthalmic, Plastic, and Reconstructive Surgery (asoprs.org).

One new feature of this year's meeting was the "ASOPRS Oculoplastics Smackdown", which tackled some controversial topics in an engaging format, including whether steroid therapy is appropriate for patients who have thyroid eye disease but no optic nerve compression and the best way to perform lower lid surgery.

In April 2016, the GDATF headed to Baltimore, MD to host a patient education event and to exhibit at the annual meeting of the American Association of Endocrine Surgeons. Endocrinologist Dr. David Cooper, Director, Thyroid Clinic, Johns Hopkins Medicine and Dawn M. Elfenbein, MD, MPH, Clinical Instructor, Surgery, University of California, Irvine School of Medicine fielded questions from patients on Graves' disease, autoimmunity, and thyroid eye disease.

In May, the GDATF hosted a full-day patient education event at University of California Shiley Eye Institute. The first part of the event was devoted to presentations on Graves' eye disease (also called thyroid eye disease) from physicians at UC San Diego Shiley Eye Institute. Presentations included:

- "Ophthalmic manifestations of thyroid eye disease and update on medical therapy" from Bobby S. Korn, MD, PhD

1 The American Thyroid Association and American Association of Clinical Endocrinologists Taskforce on Hyperthyroidism and Other Causes of Thyrotoxicosis, Rebecca S. Bahn, et al.. *Thyroid*. June 2011, 21(6): 593-646. doi:10.1089/thy.2010.0417.

- "Orbital and Eyelid Surgery in Thyroid Eye Disease" from Don O. Kikkawa, MD
- "Strabismus in Thyroid Eye Disease" from David B. Granet, MD

The presentations on thyroid eye disease were followed with a question and answer session featuring all three presenters.

The morning session concluded with two patient panels, featuring patients who were living with Graves' disease and thyroid eye disease.

The afternoon presentations focused on treatment options for Graves' disease. An attendee question and answer session followed each presentation. Presentations included:

- "An Endocrinologist's view of Graves Disease" from Karen McCowen, MD
- "Radioactive Iodine for Diagnosis and Treatment of Graves' Disease" from Farshad Moradi, MD, PhD
- "Thyroid Surgery for Graves Disease" from Kevin Brumund, MD

All three afternoon presenters are affiliated with University of California San Diego.

The program concluded with a support group session where attendees were allowed to discuss their questions and concerns in a small group setting. There were separate groups for Graves' patients, thyroid eye disease patients, and for family members of patients. Facilitators were GDATF Board Co-Chairs Steve and Kathleen Flynn and GDATF Executive Director/CEO Kimberly Dorris.

### **GDATF Board Updates**

The Graves' Disease & Thyroid Foundation extends our best wishes to Dr. Lawrence C. Wood, who announced his retirement from the GDATF Board of Directors after serving two three-year terms. GDATF Founder and Chair Emeritus Nancy Hord Patterson, Ph.D., noted, "Dr. Wood has been a pioneer in the area of patient support and education for decades. He is known and respected throughout the world, and has been my /our friend, mentor and colleague through all these years." As we say a fond farewell to Dr. Wood, Carla DiMare and Ashok Bhaseen join the GDATF as the organization's newest Board members. Carla is a trial attorney in California and Massachusetts who specializes in civil litigation and social justice issues. Ashok worked with Abbott Pharmaceuticals (Canada and International) for 12 years and has served as the Global President of Thyroid Federation International since 2011.

# TFI Member Organizations

## AUSTRALIA

*The Australian Thyroid Foundation Ltd.*

Suite 2, 8 Melville Street  
Parramatta, NSW 2150 Australia  
[www.thyroidfoundation.com.au](http://www.thyroidfoundation.com.au)

## BELGIUM

*Leven Zonder Schildklier*

Belgium  
[www.levenzonderschildklier.be](http://www.levenzonderschildklier.be)

## BRAZIL

*Instituto da Tiróide*

Rua Artur Ramos, 96 – 5A  
01454-903 São Paulo, S Brazil  
[medneto@uol.com.br](mailto:medneto@uol.com.br)  
[www.indatir.org.br](http://www.indatir.org.br)

## CANADA

*Thyroid Foundation of Canada*

*La Fondation canadienne de la Thyroïde*

PO Box 298,  
Bath ON K0H 1G0 Canada  
[www.thyroid.ca](http://www.thyroid.ca)

## DENMARK

*Thyreoidea Landsforeningen*

Strandkrogen 4C  
3630 Jaegerspris, Denmark  
[www.thyreoidea.dk](http://www.thyreoidea.dk)  
[www.stofskifteforeningen.dk](http://www.stofskifteforeningen.dk)

## FINLAND

*Suomen Kilpirauhasliitto ry*

Vilhonkatu 4 B  
FI 00100 Helsinki, Finland  
[www.kilpirauhasliitto.fi](http://www.kilpirauhasliitto.fi)

## FRANCE

*Association Vivre sans Thyroïde*

2, av d'Expert  
Léguevin 31490, France  
[www.forum-thyroïde.net](http://www.forum-thyroïde.net)

## GEORGIA (EU)

*Georgian Union of Diabetes and Endocrine Associations*

National Centre for Diabetes Research  
1, Chachavha str, fl. 4  
Tbilisi, 0159, Georgia (EU)  
[diabet@access.sanet.ge](mailto:diabet@access.sanet.ge)

## GERMANY

*Bundesverband Schilddrüsenkrebs*

*– Ohne Schilddrüse leben e. V.*

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[www.sd-krebs.de](http://www.sd-krebs.de)

*Schilddrüsen-Liga Deutschland e.V.*

Ev. Kliniken Bonn GmbH,

Waldkrankenhaus

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## NORWAY

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Fr. Nansens plass 9, NO-0160

Oslo, Norway

[www.stoffskifte.org](http://www.stoffskifte.org)

## PHILIPPINES

*Thyroid Council of the Philippines*

Room 1101, North Tower, CHBC

St Luke's Medical Center

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## PORTUGAL

*Associação das Doenças da Tiróide*

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## RUSSIA

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## SPAIN

*Asociación Española de Cáncer de Tiroides*

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## SWEDEN

*Svenska Sköldkörtelföreningen*

Postbox 10256, SE-43423

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[www.skoldkortel.se](http://www.skoldkortel.se)

## UNITED KINGDOM

*British Thyroid Foundation*

2nd floor, 3 Devonshire Place

Harrogate HG1 4AA UK

[www.btf-thyroid.org](http://www.btf-thyroid.org)

## UNITED STATES OF AMERICA

*Graves' Disease & Thyroid Foundation*

P. O. Box 2793, Rancho Santa Fe,

CA 92067, USA

[www.gdatf.org](http://www.gdatf.org)



[www.thyroid-fed.org](http://www.thyroid-fed.org)